Engaging Patients and Families in Improving Quality and Safety—The Québec model (Canada)

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Chaire de recherche en évaluation des technologies et des pratiques de pointe
Engagement des citoyens et des patients dans la transformation des organisations et du système de santé

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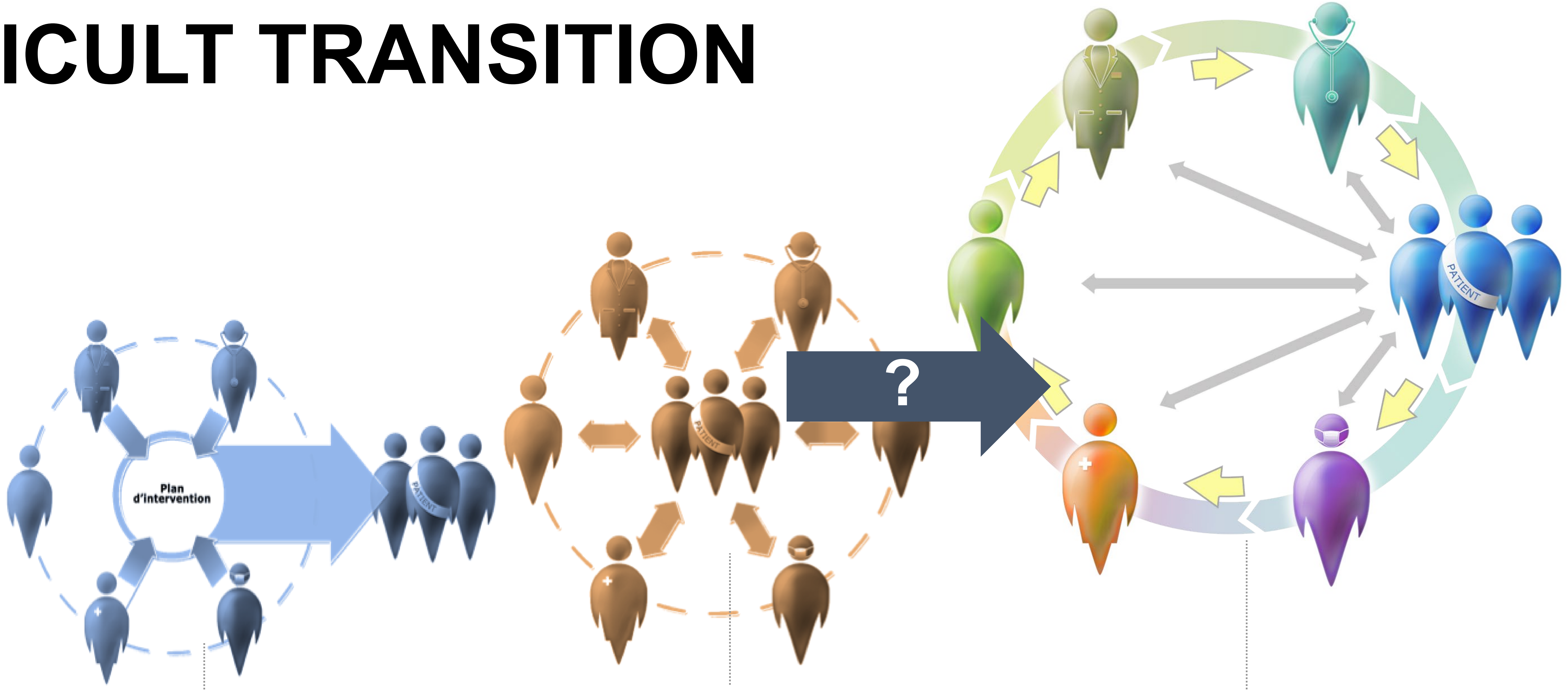
Definitions

FROM CENTRISM TO PARTNERSHIP: A DIFFICULT TRANSITION



TOWARD THE PATIENT
PATERNALISM

FOR THE PATIENT
PATIENT CENTERED-CARE

WITH THE PATIENT
PARTNERSHIP

The Patient Partnership Model … A Cultural Shift

Health professionals
Experts in disease

RECOGNITION AND MOBILIZATION OF EXPERIENTIAL KNOWLEDGE

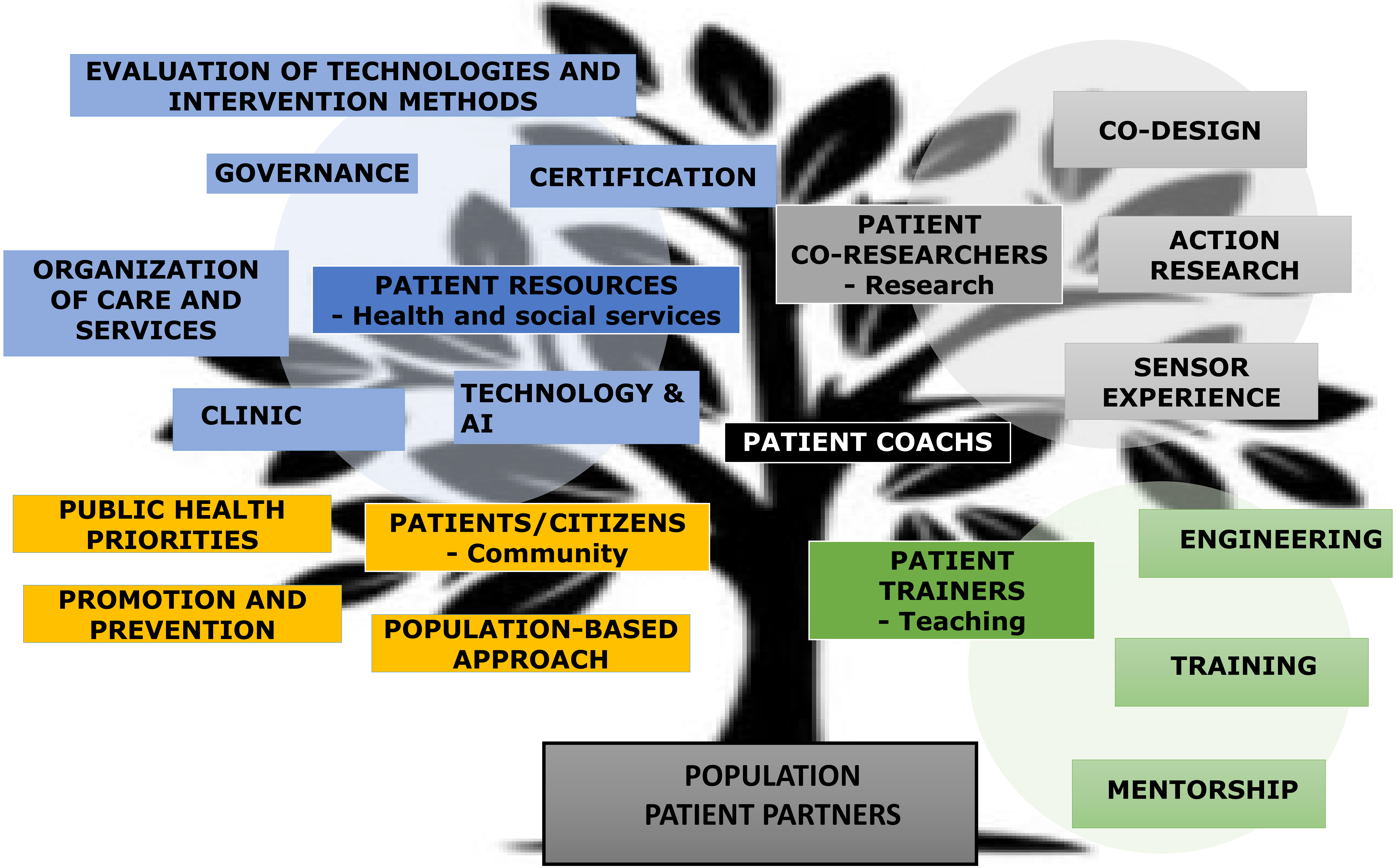
MEMBER OF THE CARE TEAM FOR THEIR CARE

VOLUNTARY AND INFORMED DECISION MAKING

MOBILIZATION OF A LIFE PROJECT

DEVELOPMENT OF CARE SKILLS

Patients and relatives
Experts in living with an illness and navigating the healthcare system



EVALUATION OF TECHNOLOGIES AND INTERVENTION METHODS

GOVERNANCE

CERTIFICATION

ORGANIZATION OF CARE AND SERVICES

PATIENT RESOURCES
- Health and social services

CLINIC

TECHNOLOGY & AI

PUBLIC HEALTH PRIORITIES

PATIENTS/CITIZENS
- Community

PROMOTION AND PREVENTION

POPULATION-BASED APPROACH

CO-DESIGN

PATIENT CO-RESEARCHERS
- Research

ACTION RESEARCH

SENSOR EXPERIENCE

PATIENT COACHS

ENGINEERING

PATIENT TRAINERS
- Teaching

TRAINING

MENTORSHIP

POPULATION
PATIENT PARTNERS

Nomenclature for mobilizing the experience of patients and citizens including AI

Principles :

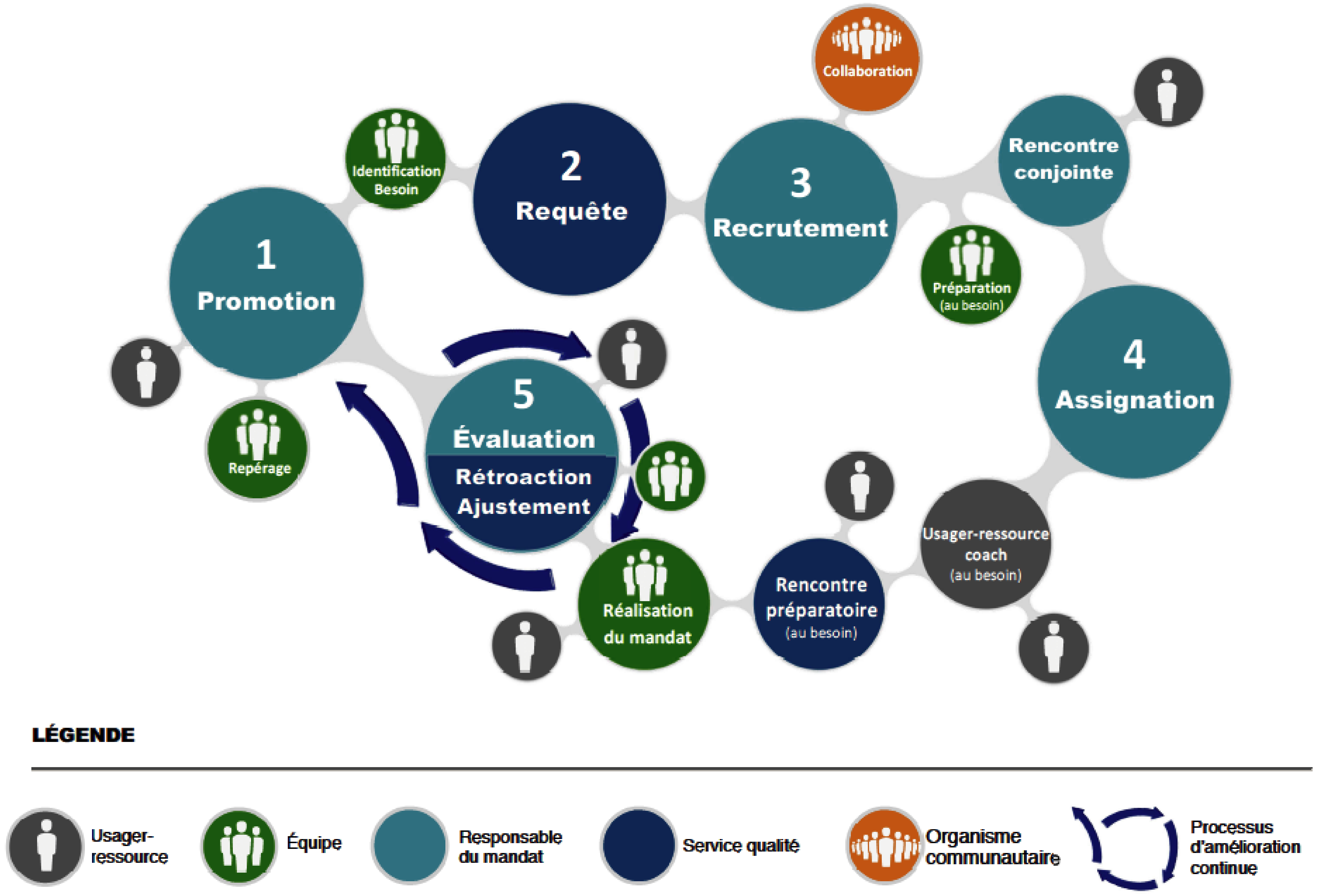
Patient partners participate

- In the selection of other patient partners
- In their training
- In their coaching

Pomey MP, et al. (2018). Healthcare Quaterly

PATIENT PARTNER INVOLVEMENT PROCESS

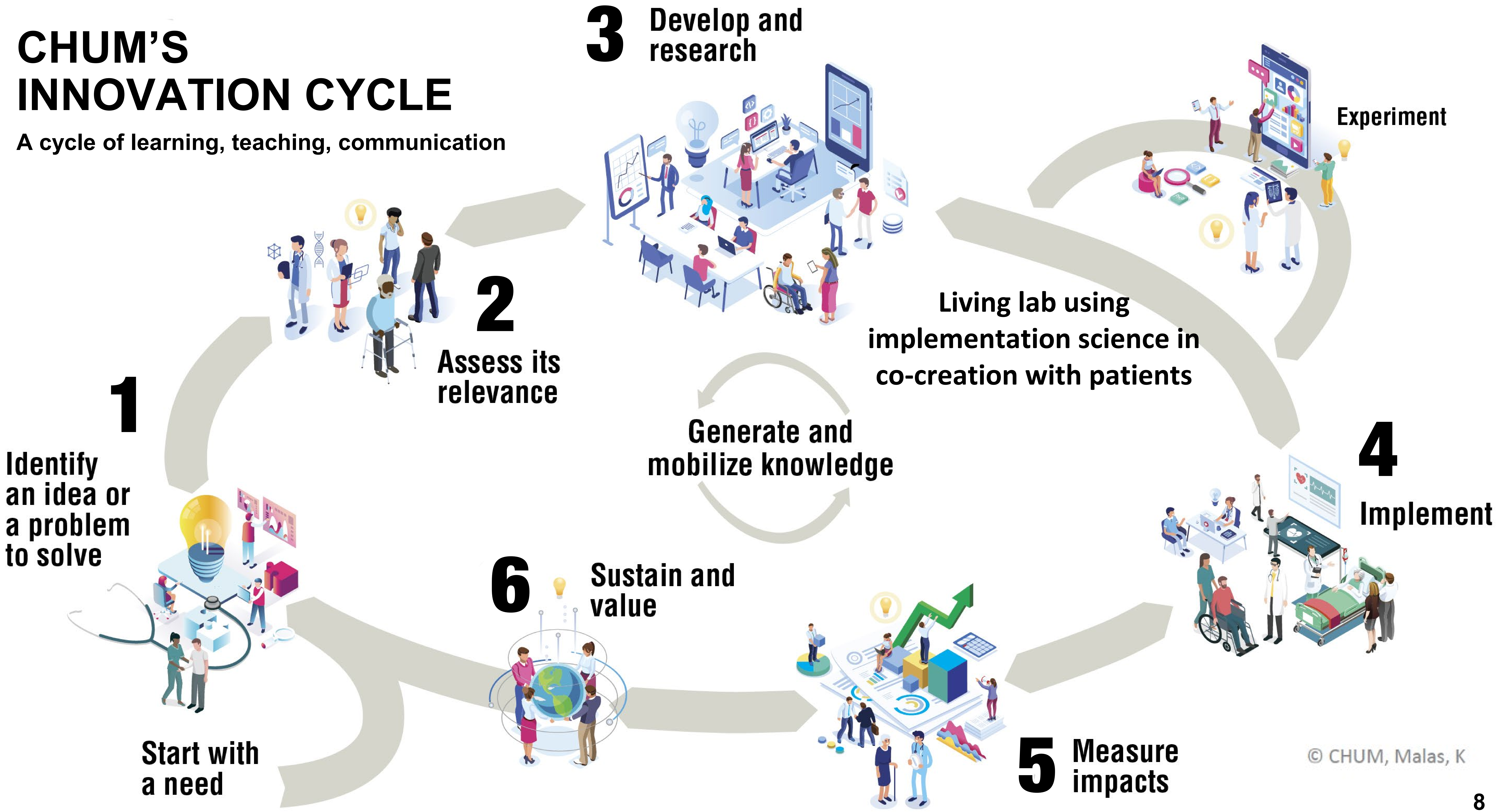
PROCESSUS D'IMPLICATION USAGER-RESSOURCE



Research working methods

CHUM'S INNOVATION CYCLE

A cycle of learning, teaching, communication



Start with a need

1 Identify an idea or a problem to solve

2 Assess its relevance

3 Develop and research

Experiment

Living lab using implementation science in co-creation with patients

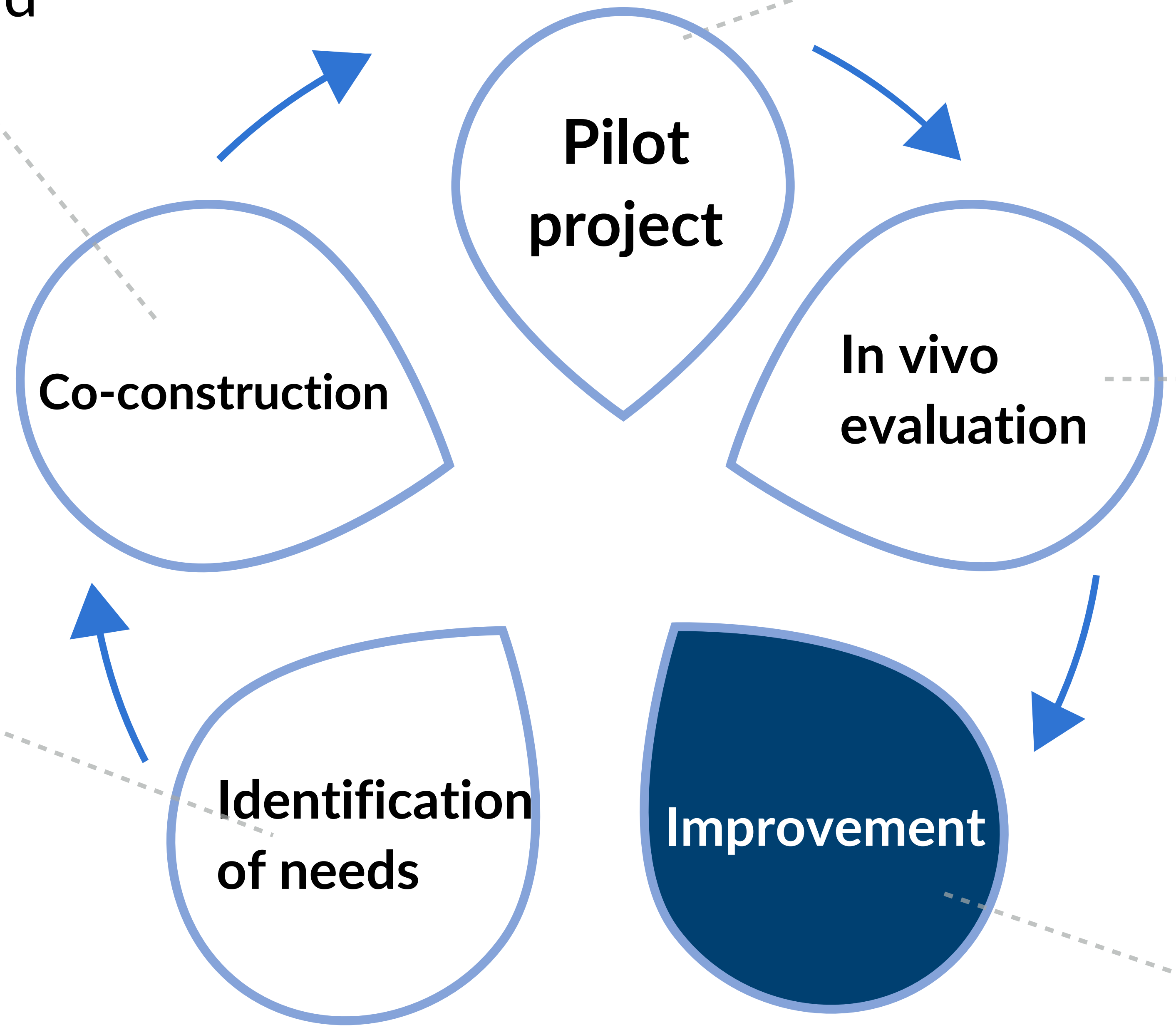
4 Implement

5 Measure impacts

6 Sustain and value

Generate and mobilize knowledge

Methodology | The co-construction laboratory in partnership (Pomey & al. 2018)



1 Identification of needs

- Identify the clinical needs
- Working with groups having different expertise including patients
- Evaluate the relevance of a peer patient program and study how that could contribute effectively.

2 Co-construction of the intervention

- Exploration of intervention targets for peer patients
- Determining the best moments and forms for the intervention

3 Pilot project

- Test and evaluate the impacts of projects with all stakeholders.
- Make the necessary adjustments
- Development of tools for the partnership between patients and professionals.
- Formal evaluation of the project by a longitudinal mixed study.

4 In vivo evaluation

Pragmatic randomized trial

Patients in the control group subject to the current treatment standard.

Patients in the intervention group subject to the current standard of practice, plus the coaching by peer patients.

Improvement and sustainability

- Changes in the organization of care
- Sustainability
- Sustainable partnerships

Pomey MP, et al. The Partnership Co-Design Lab: Co-constructing a Patient Advisor Programme to increase adherence to rehabilitation after upper extremity replantation. JHD. 2018;3(1):94–101..

Patient engagement at the organization level

The patient-visitor: towards a partnership in safety education and continuous quality improvement

Rethinking risk management in hospitals

- Each year, the CISSS de la Gaspésie records more than 5,000 incidents/accidents
- Few successful organizational strategies to date
- Employees have varying degrees of confidence in the reporting system.

Co-developing a model aimed at engaging patients in their own safety

Co-developing an approach to continuous quality improvement based on the experiential knowledge of users and their loved ones.

Collaborative work

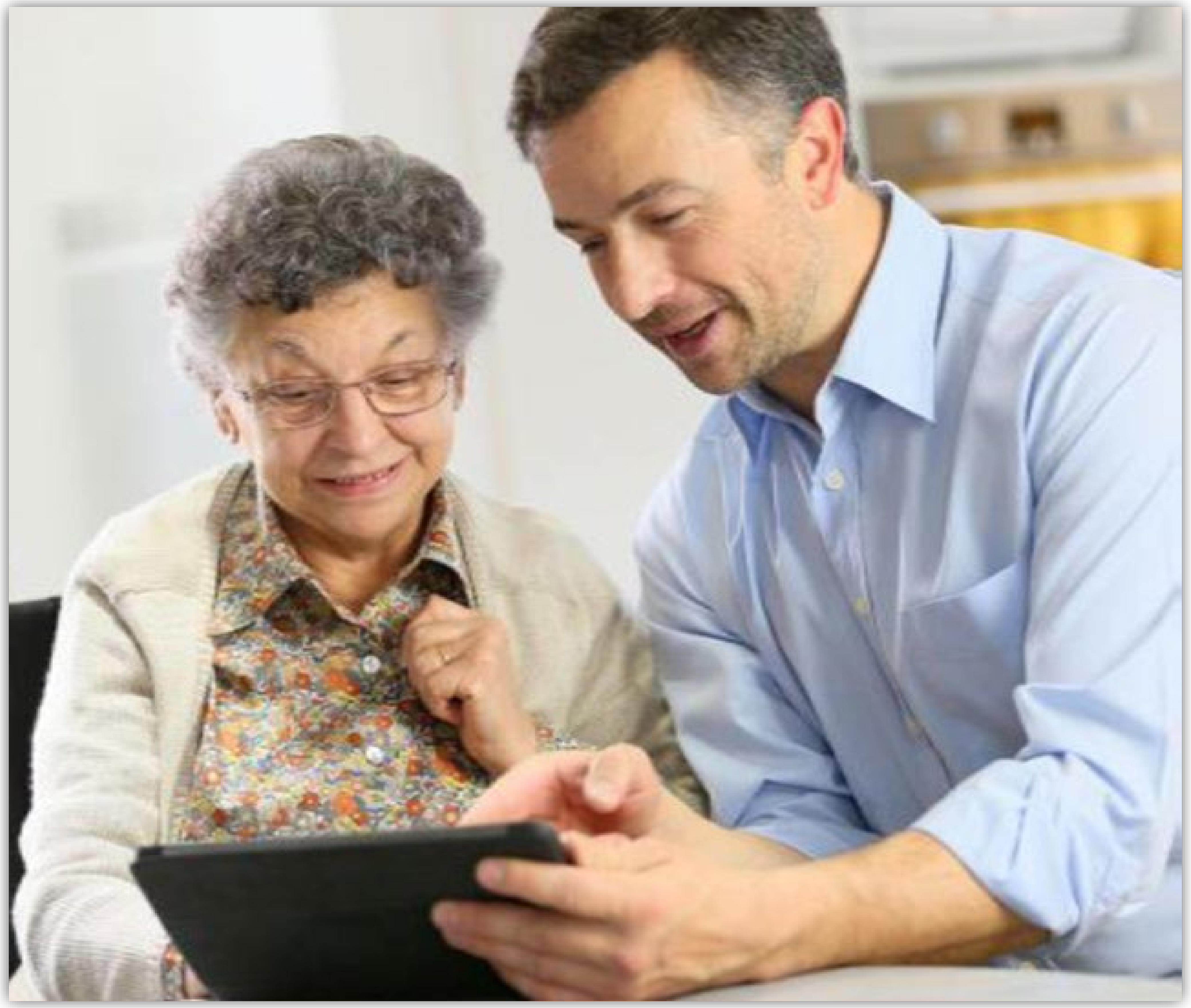
- Six patient partners who have had significant experience with healthcare
- Three nurses, assistant head nurses
- Management support team

Approach guided by three main principles

- **The active involvement of users and their loved ones** is essential to ensure their own safety
- **The commitment of healthcare teams** is necessary for an organization that constantly wants to learn from its mistakes and improve.
- Examining safety and quality through the prism of **user experience**

A New Actor: the Patient-Visitor in Risk Management

- Recruitment of patient-visitors: interest, personal experience, and strong listening and communication skills.
- Training of patient-visitors: Accreditation Canada standards, with a strong emphasis on learning by doing and co-construction.
- Collaborative work with care teams.
- Visits by patient visitors to the wards to meet with hospitalized patients and discuss their stay and any situations they found to be at risk
- **For the research : 120 patients visited in 2019 and 2021 and 8 patient visitors recruited**



Learning from the Patient Experience

- Patients are often uncomfortable disclosing risks to professionals but share them more openly with patient-visitors
- The risks identified are different from those identified by professionals
- Most patients understand the risks, but many minimize them: highlights the importance of training patients to be vigilant about safety.
- The patient-visitor is an excellent peer educator.
- The facilitator nurse in risk management is a key to success.
- Encourage progress rather than stigmatizing errors.

Winning Strategies

Patient-Visitors

- Motivated by their concrete and decision-making involvement in the project.
- Supported both financially and personally.

Facilitator Nurses

- Released from their regular responsibilities during patient-experience measurement days.
- Act as a liaison between care teams and patient-visitors (professional acceptability, support for patient-visitors, rapid corrective actions in the field).

Care Teams

- Work alongside patient-visitors in the field, sharing experiences in real time, and are informed about visits.
- Meet with patient-visitors to review findings and determine a shared improvement plan.

Patient engagement at the clinical level

Added value of Peer patients in clinical team: The liver transplant experience

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Preprints (earlier versions) of this paper are available at https://preprints.jmir.org/preprint/54440, first published November 16, 2023.

Telehealth-Delivered Program and Accompanying Patients to Enhance the Clinical Condition of Patients Throughout a Liver Transplant: Protocol for a Mixed Methods Study

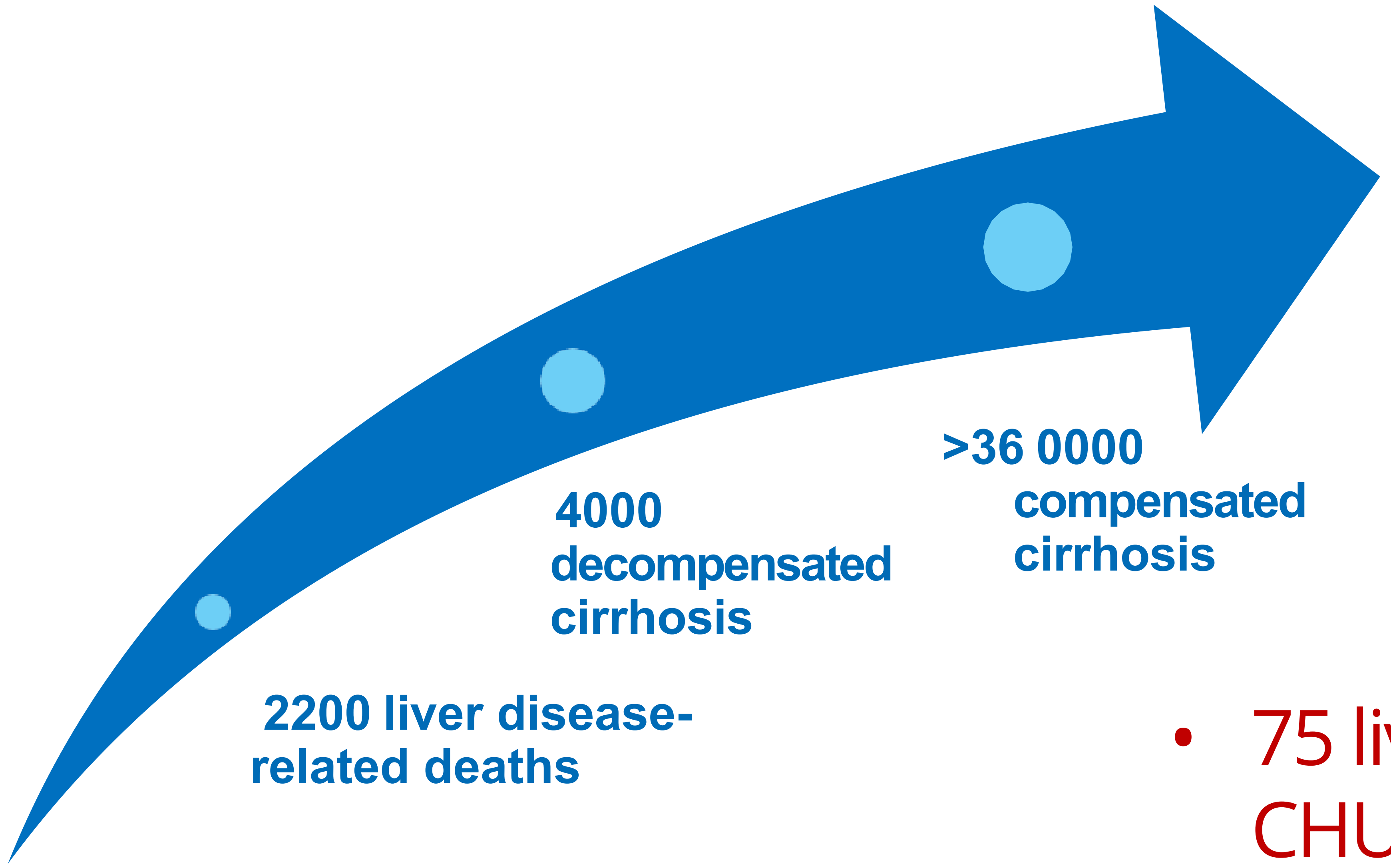
Marie-Pascale Pomey[1, 2, 3]; Enora Le Roux[1, 4, 5]; Nathalie Nadon[1]; Jessie Perron[1, 6]; Angèle Barry[1, 7, 8]; Chantal Bémeur[9]; Thomas G Poder[2, 10]; Fernand Duford[11]; Louise Laviolette[11]; Johanne Tétrault-Lassonde[11]; Cécile Vialaron[1]; Manuel J Escalona[1]; Louise Normandin[1]; Geneviève Huard[7, 11]; Catherine Girardin[7, 11]; Christopher Rose[9]; Kathy Malas[1]; Denis Ouellet[12]; Catherine Vincent[7, 11]

Liver diseases: a public health issue

- In Canada: 1 in out of 4 people
- Among the 10 main causes of death

Complications of chronic liver disease

- Malnutrition (65-95%)
- Hepatic encephalopathy
- Impaired muscle function (sarcopenia)



>36 0000 compensated cirrhosis

4000 decompensated cirrhosis

2200 liver disease-related deaths

- 75 liver transplants performed at the CHUM each year

LABO HÉPATONEURO

Sanabria et al., 2013; Morris et al., 2013; Myers et al., 2014; Fondation canadienne du foie, 2016

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Objectives

Primary objective

Propose a new integrated care model that includes a complex intervention aimed at transforming the liver transplant journey, improving patient quality and safety, and enhancing the patient experience.

Complex intervention

- an interdisciplinary clinical team that includes a physician, nurse, nutritionist, physical therapist, social worker, psychologist, and peer patient (peer support)
- connected devices to enable patients and staff to monitor changes in lifestyle habits and their effects on health
- plans for improving lifestyle habits in terms of nutrition and physical activity, developed jointly by patients according to their abilities, reviewed regularly with professionals, and encouraged by Aps
- a digital learning path to improve knowledge and develop skills in caring for patients and their loved ones

Six peer patients involved


Louise Laviolette


Fernand Duford


Luc Archambault


Colette Bérubé


Johanne Tétrault-Lassonde


Maya Nassar

Roles of Peer Patients

- GRIT-F :
  - perform an emotional and educational assessment of the patient
  - are involved in the decision on transplant eligibility
- Pre-transplantation:
  - Emotional monitoring and monitoring of patients' objectives throughout their care trajectory using **logbooks completed once a month**
  - Sharing information with the clinical team weekly
  - Education of patients awaiting transplant
  - Tests on connected devices and digital platform to ensure their relevance
  - Be themselves users of CDs and physical exercise plans to best support patients
  - Communicate regularly with the patient to motivate them to continue the research project

Post-transplantation:

- Sharing information with the clinical team if necessary, communicate regularly to support patient to do their physical exercise and nutritional plans

Added value for the study

- **Completion of the research project** (#3 co-researchers)
    - Review all research tools
    - Participate in data analysis

- **Project implementation** (#6)
    - Participate in 4 of the 6 committees created
    - Participate in all meetings with funders and decision-makers
    - Participate in the development of a patient learning pathway
    - Participate in the choice of connected devices
    - Participate in drawing up the patient intervention plan
    - Meet all patients at GRIT-F and the transplant list registration day

- **Implementation of research project** (#6)
    - Presentation of research project to patients
    - Complete a monthly logbook summarizing their monthly activities

Benefits for patients

- **GRIT-F :** “The PP listened to me a lot and reinforced my confidence in the team. I feel much safer” (Anthony)
  - Reduction in pre-transplant assessment time from **45 days to 5 days**
  - Reduction in patient commuting and therefore **costs for patients**
  - Reduction in time spent on the transplant list from **55 days to 7 days**
  - Reduction in risk of test loss, retesting, and deterioration of health

Benefits for patients

- **Pre-transplantation:** « I have physical exercises to do. I find it difficult, but fortunately, I can do them with my PP if I'm not motivated to do them on my own. » (Peter)
  - Significant improvement in the **6-minute walk test** while awaiting transplantation
  - Significant improvement in the **Liver Frailty Index** while awaiting transplantation
  - Decrease in the number of **medical consultations** and therefore a reduction in costs related to medical personnel
  - Decrease in the number of **hospitalizations** during this period
  - Reduction in **risks** associated with hospitalizations
  - Change in priorities on the **transplant list**

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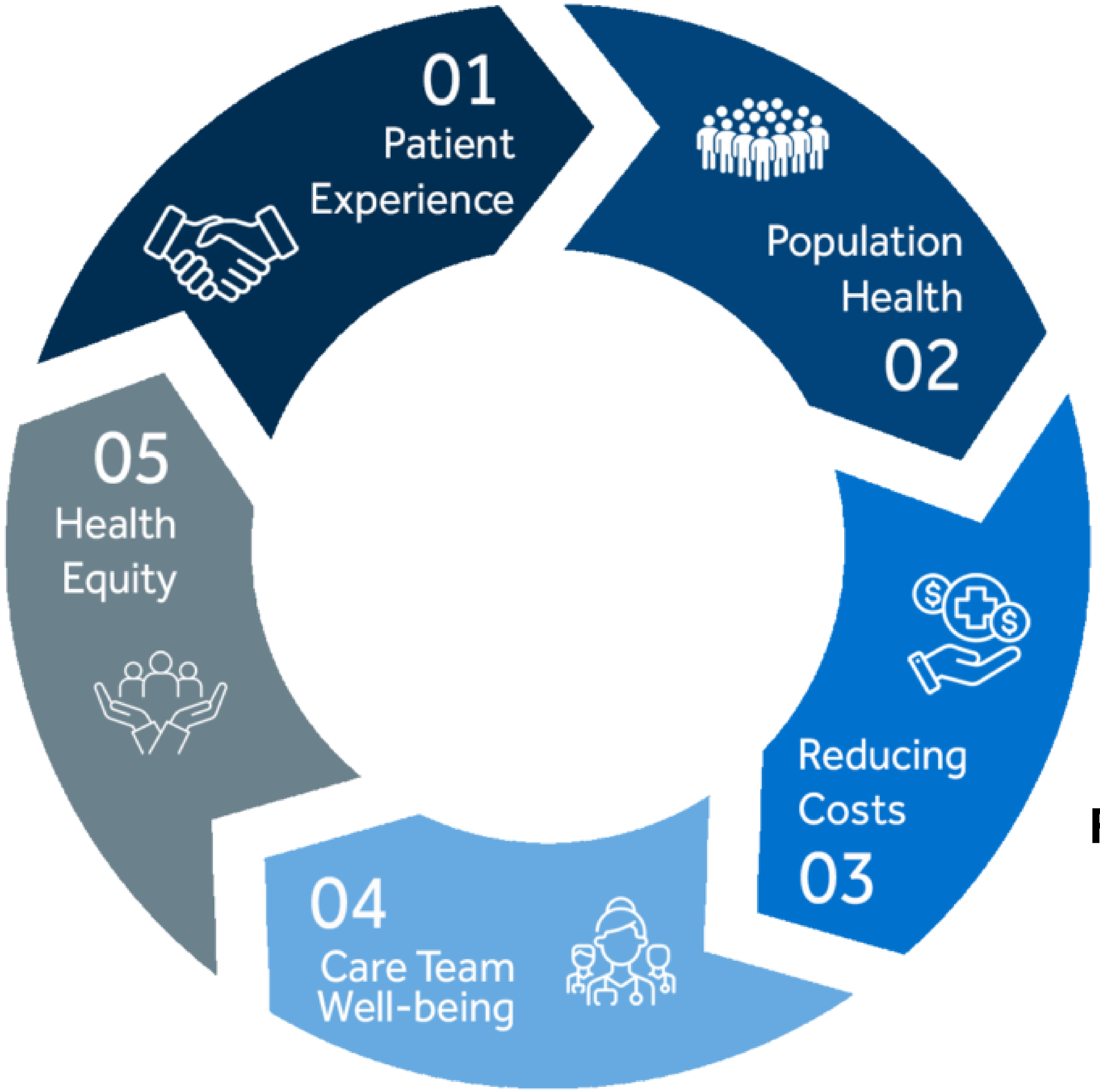
Benefits for patients

- **Pre and post-transplantation:** “I continued to do my physical exercises after the transplant. I also continued to eat well. I asked Santa Claus to give me connected devices, and now I can’t do without them.” (Charles)

- Reduction in **hospital stay** from one month to 10 days
- Resumption of **physical activity** from 6 months post-surgery to a few hours post-surgery
- Return to **work** from 6 months to one month
- Significant decrease in the number of **hospitalizations** and **medical consultations** following transplantation
- Reduction in **risks** associated with hospitalizations
- Reduction in **complications** due to physical deconditioning

Summary of preliminary results



Improved emotional, educational, informational, and navigational support

Reduced anxiety, better understanding of the journey and the disease, improved ability to become a partner in one's own care, improved trust with the clinical team

Improvement in biological constants: reduction in malnutrition, encephalopathy, and muscle loss

Faster recovery during and after transplantation

Improvement in experience and quality of life

Reducing social inequalities by enabling people who are afraid to speak up to express their implicit and explicit needs

Optimization of medical time
Reduction in length of stay per transplant
Reduction in number of consultations and hospitalizations
Reduction in travel for patients

Better integration of patients' experiences, feedback on practices, improved interprofessional collaboration, changes in practices, changes in the relationship with patients

According to the 5 objectives of IHI

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Patient engagement at the clinical level

CADICEE: A PREM to measure the partnership relationship between patients and healthcare providers

Partnership measurement

- Except for the CADICEE tool, there is no tool available to measure the level of partnership at the clinical level between a patient/user and a healthcare professional.
- The CADICEE tool was developed BY and FOR patients/users.
- It is the first PREM (patient-reported experience measurement) in the field of partnership.
- Enable patients/relatives to assess the gap between what they want in terms of partnership in care and services with their healthcare professionals and the reality.
- Be able to discuss with healthcare professionals how to establish a partnership.

Partnership measurement

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ORIGINAL RESEARCH PAPER

WILEY

Assessing and promoting partnership between patients and health-care professionals: Co-construction of the CADICEE tool for patients and their relatives

Marie-Pascale Pomey[1,2,3] | Nathalie Clavel[4] | Louise Normandin[2] | Claudio Del Grande[1,2] | Djahanchah Philip Ghadiri[5] | Isabel Fernandez-McAuley[2] | Antoine Boivin[6] | Luigi Flora[7] | Annie Janvier[8] | Philippe Karazivan[3,5] | Jean-François Pelletier[9] | Nicolas Fernandez[10] | Jesseca Paquette[2] | Vincent Dumez[3,11]

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Abstract

Context: Partnership between patients and health-care professionals (HCPs) is a concept that needs a valid, practical measure to facilitate its use by patients and HCPs.

Objective: To co-construct a tool for measuring the degree of partnership between patients and HCPs.

Design: The CADICEE tool was developed in four steps: (1) generate key dimensions of patient partnership in clinical care; (2) co-construct the tool; (3) assess face and content validity from patients' and HCPs' viewpoints; and (4) assess the usability of the tool and explore its measurement performance.

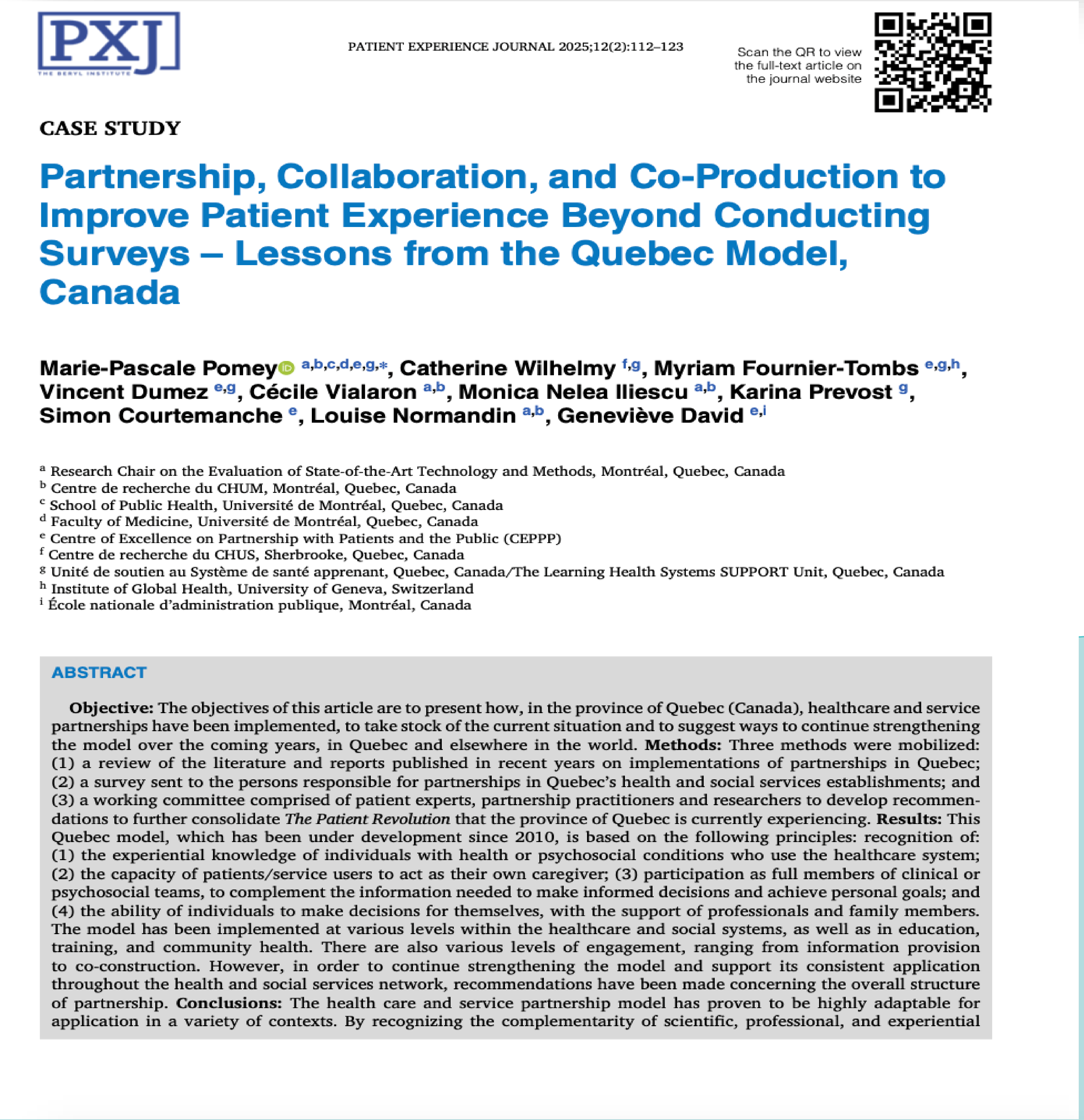
Results: The CADICEE tool comprises 24 items under 7 dimensions: 1) relationship of Confidence or trust between the patient and the HCPs; 2) patient Autonomy; 3) patient participation in Decisions related to care; 4) shared Information on patient health status or care; 5) patient personal Context; 6) Empathy; and 7) recognition of

Mutual **Trust (Confiance)**,
User **Autonomy**,
User participation in **Decision**-making regarding their care,
Shared **Information** about the user's health status or care,
Consideration of the user's life **Context**,
Mutual **Empathy** between the user and the healthcare professional;
Recognition of mutual **Expertise**.

Patient partnership engagement

A tool Box

To know more about the Quebec Model



PXJ

PATIENT EXPERIENCE JOURNAL 2025;12(2):112–123

Scan the QR to view the full-text article on the journal website

CASE STUDY

Partnership, Collaboration, and Co-Production to Improve Patient Experience Beyond Conducting Surveys – Lessons from the Quebec Model, Canada

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ABSTRACT

Objective: The objectives of this article are to present how, in the province of Quebec (Canada), healthcare and service partnerships have been implemented, to take stock of the current situation and to suggest ways to continue strengthening the model over the coming years, in Quebec and elsewhere in the world. **Methods:** Three methods were mobilized: (1) a review of the literature and reports published in recent years on implementations of partnerships in Quebec; (2) a survey sent to the persons responsible for partnerships in Quebec's health and social services establishments; and (3) a working committee comprised of patient experts, partnership practitioners and researchers to develop recommendations to further consolidate *The Patient Revolution* that the province of Quebec is currently experiencing. **Results:** This Quebec model, which has been under development since 2010, is based on the following principles: recognition of: (1) the experiential knowledge of individuals with health or psychosocial conditions who use the healthcare system; (2) the capacity of patients/service users to act as their own caregiver; (3) participation as full members of clinical or psychosocial teams, to complement the information needed to make informed decisions and achieve personal goals; and (4) the ability of individuals to make decisions for themselves, with the support of professionals and family members. The model has been implemented at various levels within the healthcare and social systems, as well as in education, training, and community health. There are also various levels of engagement, ranging from information provision to co-construction. However, in order to continue strengthening the model and support its consistent application throughout the health and social services network, recommendations have been made concerning the overall structure of partnership. **Conclusions:** The health care and service partnership model has proven to be highly adaptable for application in a variety of contexts. By recognizing the complementarity of scientific, professional, and experiential

https://pxjournal.org/journal/vol12/iss2/19/

Sources to find tools

- The Center of Excellence on Patient and Public Partnership
  https://ceppp.ca/ressources/

- The Support Unit
  https://ssaquebec.ca/boite-a-outils/

- Chair in Technology and Practice Assessment
  https://chaireengagementpatient.openum.ca/boite-a-outils/soutien-par-les-paires/

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Patient partnership engagement

Appendix

Experiential knowledge is ...

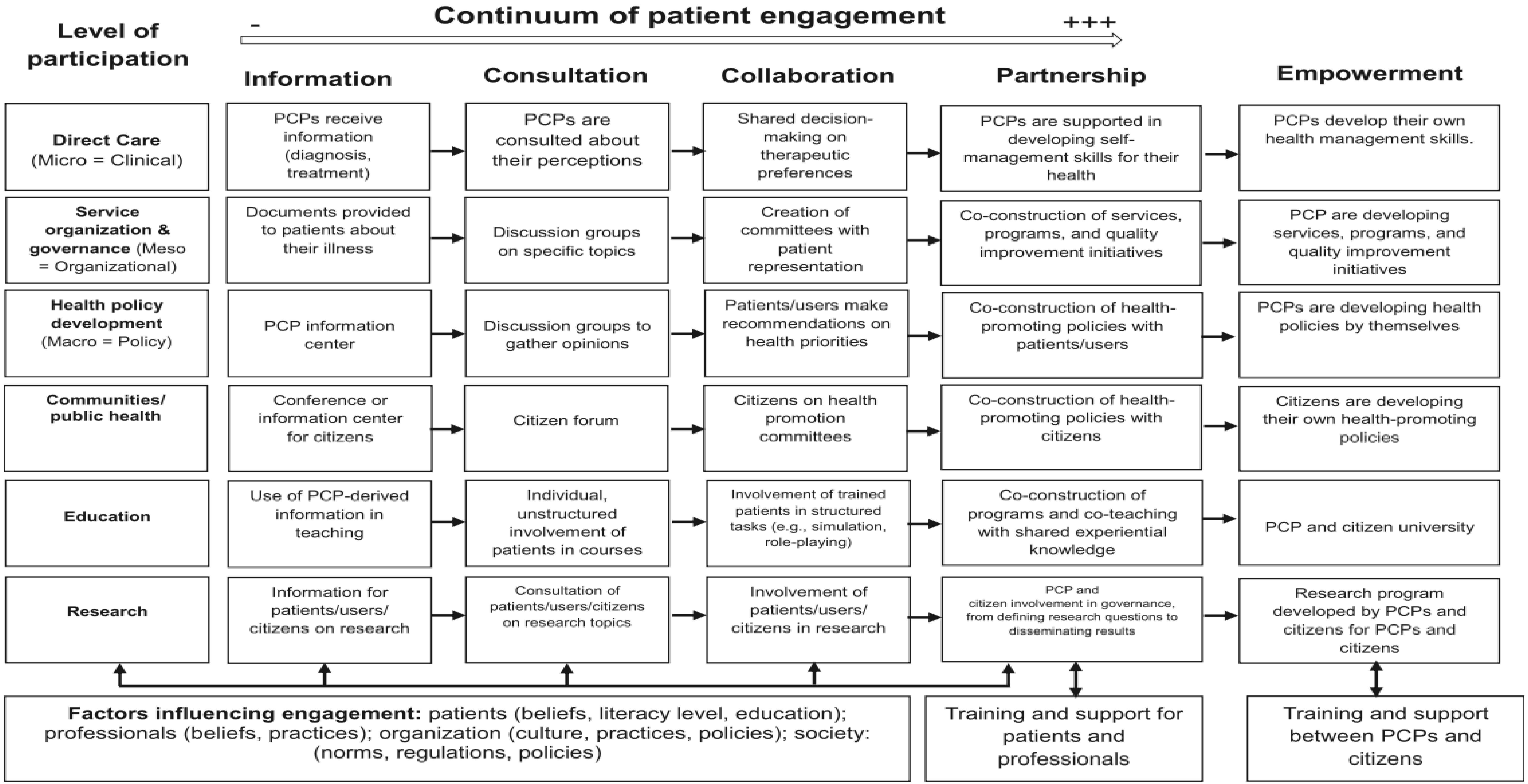
All the knowledge acquired (i.e., know-how, interpersonal skills) from experiences (in informal or formal settings) with a health or disability situation that has had an impact on the person, in terms of how they take care of themselves, how they interact with care providers, and how they use health and social services.

In living with a given state of health or disability, the person finds an opportunity to develop new skills, move toward self-transformation through the experience and, therefore, move the lines of knowledge sharing.

A lifelong experience for individuals who are coping with a chronic illness or disability.

(inspired by the *Lexique DCPP et CIO-UdM (2016), Terminologie de la pratique collaborative et du partenariat patient en santé et services sociaux*; DCPP (2015) Référentiel de compétences des patients. Montreal, Quebec: Faculty of Medicine, Université de Montréal; Jouet, 2011)

Level of engagement



Continuum of patient engagement

- +++

Level of participation	Information	Consultation	Collaboration	Partnership	Empowerment
Direct Care (Micro = Clinical)	PCPs receive information (diagnosis, treatment)	PCPs are consulted about their perceptions	Shared decision-making on therapeutic preferences	PCPs are supported in developing self-management skills for their health	PCPs develop their own health management skills.
Service organization & governance (Meso = Organizational)	Documents provided to patients about their illness	Discussion groups on specific topics	Creation of committees with patient representation	Co-construction of services, programs, and quality improvement initiatives	PCP are developing services, programs, and quality improvement initiatives
Health policy development (Macro = Policy)	PCP information center	Discussion groups to gather opinions	Patients/users make recommendations on health priorities	Co-construction of health-promoting policies with patients/users	PCPs are developing health policies by themselves
Communities/ public health	Conference or information center for citizens	Citizen forum	Citizens on health promotion committees	Co-construction of health-promoting policies with citizens	Citizens are developing their own health-promoting policies
Education	Use of PCP-derived information in teaching	Individual, unstructured involvement of patients in courses	Involvement of trained patients in structured tasks (e.g., simulation, role-playing)	Co-construction of programs and co-teaching with shared experiential knowledge	PCP and citizen university
Research	Information for patients/users/ citizens on research	Consultation of patients/users/citizens on research topics	Involvement of patients/users/ citizens in research	PCP and citizen involvement in governance, from defining research questions to disseminating results	Research program developed by PCPs and citizens for PCPs and citizens

Factors influencing engagement: patients (beliefs, literacy level, education); professionals (beliefs, practices); organization (culture, practices, policies); society: (norms, regulations, policies)

Training and support for patients and professionals

Training and support between PCPs and citizens

Fig. 1. The Quebec Model.[1,6]

Source: Pomey MP et al. (2025).. Partnership, Collaboration, and Co-Production to Improve Patient Experience Beyond Conducting Surveys – Lessons from the Quebec Model, Canada. Patient Experience Journal. 2025; 12(2):112-123. doi: 10.35680/2372-0247.2039. https://pxjournal.org/journal/vol12/iss2/19/

Selection criteria for patient or relative partners

Care experience	- Having lived at least one treatment experience in the concerned trajectory. - Having gained perspective with regard to their illness and care trajectory. - Having received treatments in the establishment where the AP wishes to practice. - Being psychologically and emotionally stable. - Having respected the treatment and follow-up plans determined by the clinical team.
Communication and collaboration abilities	- Possess listening and empathy skills - Express oneself clearly and simply - Express a constructive attitude in one's interventions concerning the healthcare system in general - Possess a constructive critical mind - Be able to generalize one's experience to other healthcare contexts
Motivation	- Being available and motivated to implicate oneself with the clinical team and patients during the program's implementation. - Demonstrating a desire to help people and contributing to an objective that transcends individuality.
Philosophy	- Understanding the visions and the implications of the care partnership model, and of the health services. - Not being in conflict with the establishment or with a person from the establishment

Tool box to measure

- The contribution of patient researchers to research work
- A guide and tools for integrating patient advocates into clinical teams
- Tools for implementing peer patient
- Tools for evaluating the implementation of peer patient
- Tools for evaluating the effects of peer patient based on the five AIMs (see the sixth AIM)
- Learning plans for patients in different areas